Building a self-management program for workers with a chronic somatic disease
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Chapter 1

General introduction
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“When one thinks of work, one often thinks of a job. But work is far more than a job. Work is, above all, an activity through which an individual fits into the world, creates new relations, uses his talents, learns and grows, develops his identity and a sense of belonging”. (E. Morin)

The main objectives of this thesis are to investigate which problems at the workplace are experienced by workers with a chronic somatic disease and to investigate which solutions are needed from the perspective of the worker and health professionals. On the basis of the solutions offered a vocational rehabilitation program has been constructed based on the Chronic Disease Self-management Program of Stanford University aimed at self-management at work and job retention.

In the introduction of this thesis I will explore the terms chronic somatic disease, work-related problems, vocational rehabilitation and self-management at work. In the second part of the introduction I formulate research questions followed by an outline of the thesis.

1.1 Background and research questions

Definition of chronic disease

In the literature many definitions of ‘chronic condition or chronic disease’ can be found. The word ‘chronic’ is typically used for conditions, illnesses, and diseases lasting for three months or more. Often, chronic conditions are characterized by lasting symptoms that persist despite treatment. Generally, a chronic disease implies a condition that requires ongoing adjustments by the affected person and interactions with the health care systems. Chronic diseases are nowadays often described as chronic non-communicable diseases. A non-communicable disease, or NCD, is a medical condition or disease which is a non-infectious disease characterized by a long duration and slow progression.

Incidence and prevalence of chronic diseases

The World Health Organization reported in 2009 that NCDs are by far the leading cause of mortality and disability in the world, representing over 60% of all deaths. In 2008, 36.1 million people worldwide died from NCDs such as heart diseases, strokes, chronic lung diseases, cancer and diabetes. Nearly 90% of these deaths occurred in low- and middle-income countries. NCDs are a leading cause of mortality and disability and a primary driver of health care costs in the USA and Europe. It is estimated that NCDs in Europe account for approximately 86% of deaths and will affect 40% of the population over 15 years. In the United States and in the Netherlands NCDs were in 2010 responsible for approximately 90% of the deaths. The leading NCDs in developed countries include (in alphabetical order) arthritis,
cardiovascular disease such as heart attacks and stroke, cancer such as breast and colon cancer, diabetes and epilepsy. In 2008 it was estimated that 28% of the Dutch population has a NCD. The percentage of people with a NCD (self-reported) in the Netherlands is similar to the average of all the countries of the European Union. Approximately 28% of the male population and 33% of the female population in the European Union has a chronic illness. In 2007, 39% of the U.S. working age population had at least one chronic disease such as diabetes, asthma or depression. The (somatic) NCDs in the Netherlands with the highest prevalence are diabetes mellitus (740,000), arthritis (650,000), cardiovascular diseases (648,000) and hearing impairment (623,000). Prognostic studies from Europe and the US predict an increase in the next twenty years of the percent of the population diagnosed with a NCD such as asthma, chronic obstructive pulmonary diseases (COPD), or diabetes.

The impact of a chronic disease on participation
A NCD, such as RA or COPD, has a multidimensional impact on peoples’ lives, which can result in limitations in performing activities of daily life and at work, and therefore in job loss or permanent work disability. The majority of people with a chronic disease, is able to manage their disease and can carry out a relatively normal live. However, people with a NCD experience more participation problems: socially, financially and at work, than people in the general Dutch population. In 2007, 40% of the people with a NCD between the age of 16 to 64 in the Netherlands had a paid job in comparison to 66% of the general population, and one third of the employees with a chronic disease encounters problems at work because of the disease. On the other hand, many people with chronic diseases are able to lead productive lives if supported to do so.

The Chronic Care Model and self-management
In 2008 the Chronic Care Model has been introduced in the Netherlands to adjust primary care to a programmatic approach of chronic disease care. The Chronic Care Model (CCM) identifies the essential elements of a health care system that encourages high-quality chronic disease care. These elements are the community, the health system, self-management support, delivery system design, decision support and clinical information systems. The CCM is often a lead for countries to change or reorganise their healthcare system. The imbedding of self-management in primary health care is one of the goals of the Dutch government within their health program for chronic diseases. People with a chronic disease should be facilitated as much as possible to cope with their disease. In the CCM the term self-management is defined more broadly and indicates both the role of the health professional as well as the role of the patient. In the CCM it is assumed, that the clinical results of patients with a chronic disease will improve if they participate actively in their healthcare process. In the CCM one works departing from the idea of shared care or ‘collaborative care’. The health professionals should facilitate patients to manage their disease. Until now the CCM only focuses on primary health care. Occupational health care is until now not a part of primary health care. The WHO defined primary health care to be the first level of contact of individuals, the family and community with the national health system, bringing health care as closely as possible
to where people live and work. In the resolution of the 60th World Health Assembly a plan of action has been adopted to the end of strengthening the development of human resources for workers’ health. Two of the main priorities in primary health care should be: building capacity for basic occupational health services; incorporating workers’ health in the training of primary health care practitioners and other professionals needed for occupational health services.

Different authors have postulated that “scope and depth of the community resources and policy-linkage components of the CCM may need to be expanded”. New initiatives show that linking occupational and primary health care is now on the WHO agenda as certain health problems, such as NCDs, require an integrated response by primary and occupational health care and empowerment of workers.

To date there is no ‘gold standard’ definition of self-management. Rather, several terms are used, sometimes interchangeably, depending on the context and focus of the discussion. These include: self-management preparation and training; patient empowerment; and self care. Although generally they are meant to describe a similar phenomenon, the terms imply varying specifications regarding attributes, roles and responsibilities of both people with chronic health conditions and health care providers. Barlow et al. defined self-management as referring to an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition; efficacious self-management encompasses the ability to monitor one’s condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life, thus, a dynamic and continuous process of self-regulation is established. Self-management support is generally defined as the systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support. Self-management support is needed to achieve a good cooperation between the patient and the professionals.

Different self-management programs have been evaluated on different outcomes of disease-management such as quality of life, burden of disease and clinical outcomes. In a systematic review of randomized trials on diabetes mellitus self-management programs significant improvements on the outcome glucose level was found. A systematic review on the effectiveness of COPD self-management programs has found an improved lung function in some studies. One of the most frequently used generic programs is the Chronic Disease Self-Management Program of Stanford University (CDSMP) developed by Lorig et al. in 2006. The CDSMP is an example of a lay-led health education program aimed at helping participants develop a range of skills and confidence to deal more effectively with their chronic conditions. CDSMP is an empowering program designed specifically to help adults with chronic conditions manage their overall quality of life. CDSMP focuses on problems common to patients suffering from chronic diseases. Coping strategies, such as action planning and feedback, behavior modeling, problem-solving techniques, and decision making are applicable to all chronic
diseases. Patients are taught to control their symptoms through: application of relaxation techniques, exercises and pain management, changing their diets, managing sleep and fatigue, using medication correctly, improving communication with health providers, and utilizing peer and/or family support.

A Cochrane review on the effectiveness of self-management programs by lay leaders, including the CDSMP, shows that these programs can lead to short-term improvements in patients’ confidence to manage their condition and to positive health-outcomes. There were also significant improvements in cognitive symptom management of pain, disability, fatigue and depression. The CDSMP has been shown to improve self-efficacy, self-management behavior and health status, while reducing hospitalization and emergency visits. These self-management programs focus on managing the disease in general and do not specially apply for workers with a chronic disease.

**Occupational health interventions**

In traditional occupational health interventions, the client had a rather passive role. It is a rather new phenomenon especially in the past decades that occupational health interventions have also focused on empowerment and health promotion among workers. In the Netherlands, a recent law on work disability pension legislation (Work and Income according to Labour Capacity Act) [Wet Werk en Inkomen naar Arbeidsvermogen, WIA]) has made employees and employers themselves more responsible for job retention. A recent evaluation of the WIA has shown that it is difficult to measure the impact of this law. Workplace based interventions most commonly include assessing exposure to risk factors of work, work accommodations, disability management strategies (e.g. early contact with the worker), ergonomic work site visits and education and training provided to supervisors, workers and casemanagers. Workplace based programs are mostly disease specific (low back-pain, nervous exhaustion, cancer survivors or RSI) and they do not always include or focus on the training of skills and on behavior change of the employee such as on increasing the self-efficacy of the employee to deal with the disease at work and on related problems at work. Self-management is a success when the expectations of the person with a chronic disease change from the expectation that the problem can only be solved by the health professionals or the employer to the belief that the problem can also be (partly) solved by the person him- or herself. Studies based on the patient’s and health professionals’ perspective provide information that employees with a chronic disease need to acquire knowledge and skills to cope with the problems encountered at work because of their chronic disease. There is some evidence that occupational health interventions for employees with a chronic disease based on the empowerment perspective are effective. These programs are aimed at improving psychosocial skills or implementing work accommodations. The interventions are all disease specific like for example end-stage renal disease, noise-induced hearing loss or rheumatic diseases. Not many generic vocational rehabilitations programs have been developed and evaluated until now. One of the few generic self-management programs aimed at job retention which have been evaluated is a study by Varekamp et al. 2011. After 24 months, self-efficacy increased and fatigue decreased significantly more in the experimental than in the control group.
Chapter 1

The aim of the vocational rehabilitation program based on the CDSMP that has been developed in this study focuses on self-management (behavior) at work. Self-management is referred to as an outcome and describes workers’ attitudes, skills, and behaviors towards self-management at work. For example, the worker has knowledge of his condition and adopts a self-management care plan in cooperation with a health professional, or employer (supervisor, manager). The worker can communicate to his employer and colleagues what the symptoms are of the chronic disease and what he needs to be able to function at work. The worker monitors and manages the symptoms of his condition and adopts a healthy lifestyle. Furthermore the worker is aware of and uses resources and support services. Until now, the CDSMP has not been tested on work related outcomes, but only on disease related outcomes. The original CDSMP focuses on personal factors like lifestyle and disease-related factors like coping with symptoms of the disease but does not focus on e.g. work-related perception and behavior such as self-management behavior at work.

Research presented in this thesis
In this thesis we constructed a vocational rehabilitation program based on the CDSMP. The aim of the program is to support employees with a chronic illness to find solutions at the workplace. In this thesis we focus on the work ability of employees with a chronic somatic disease, like for example rheumatoid arthritis, COPD, diabetes mellitus or coronary heart disease. The intervention has been tested and the results are described in this thesis.

1.2 Research questions thesis

The main research questions answered in this thesis are:
1) Which problems are encountered by workers with a chronic somatic disease during work? (chapter 2-4)
2) Which solutions are possibly needed for workers with a chronic somatic disease to stay at work? (chapter 2-4)
3) Which prognostic factors for work disability are common for different chronic somatic diseases? (chapter 5 and Appendix)
4) Does the CDSMP fit well to approach the problems of workers with a chronic somatic disease, and which adaptations are needed to tailor the intervention for workers with a chronic somatic disease? (chapter 6)
5) Which elements of the training have been positively and negatively evaluated by the participants? (chapter 7)
6) Does the CDSMP for work produce the intended outcome on the expected process and impact variables as described in the CDSMP for work model? (chapter 8)
1.3 Outline Thesis

The research project knows two phases. In the first part of the project the self-management program for workers, the *CDSMP for work* program, was in a development phase. This program was designed based on the original Chronic Disease Self-Management Program of Stanford University, theories of behavior change, concept mapping studies with workers and health professionals, and a systematic literature study. The development phase is described in chapter 2 to chapter 6. In chapter 2, 3 and 4 the results of the focus groups with workers and health professionals are presented. In chapter 5 the results of the systematic literature review on the common prognostic factors of work disability among workers with a chronic disease are described. In chapter 6 the results are presented of the systematic development of the training according to the intervention mapping protocol. In the second part of the project, the evaluation of the *CDSMP for work* program is specified in chapters 7 and 8. In chapter 7 we present the results of the interviews with participants of the course, in chapter 8 the results of the randomized controlled trial. In chapter 9, the results of the research project are discussed including conclusive remarks.
1.4 References

1. Morin EM. The meaning of work in modern times. Proceedings of the 10th World Congress on Human Resources Management; 2004 August 20; Rio de Janeiro Brazil.


